Dear Editor:

In an effort to increase awareness, those of us living with hydrocephalus are reaching out to our broader communities and our representatives in Washington, D.C., to educate them on the impact of this disease on our lives and the urgent need for better treatments. Nearly one million people across the United States – including children, seniors, and increasingly our veterans – are living with hydrocephalus, a disease characterized by excess cerebrospinal fluid in the brain.

Hydrocephalus can be diagnosed at birth or it can be the result of an injury or illness. A certain form of the disease simply develops with age and can be easily misdiagnosed as Alzheimer’s or Parkinson’s, though many of the devastating symptoms can be reversed with surgery. Experts also suspect that hydrocephalus has or will develop in two-thirds of our Armed Forces with moderate or severe traumatic brain injuries (TBI).

While treatable, people living with hydrocephalus, like my [INSERT YOUR WORDS], face the prospect of dozens of brain surgeries throughout their lifetime as one out of every two shunts implanted to treat this condition fails within two years – the highest failure rate of any implantable medical device. In my family, hydrocephalus...[INSERT YOUR WORDS]

Please join me in calling on our representatives in Washington to support a significant expansion of the National Institutes of Health’s (NIH) current efforts to establish a broader collaborative research effort into the incidence, causes and treatments of hydrocephalus. Additionally, our legislators should be contacting the Department of Defense (DoD) to gain a better understanding of how many of our veterans are now living with hydrocephalus, to learn how many federal dollars are now being used to treat hydrocephalus, and to ensure that research dollars focused on traumatic brain injuries (TBI) are available to help develop a cure for hydrocephalus.

New, basic and clinical research, through either the National Institutes of Health (NIH) or the Department of Defense (DOD) will not only benefit the one million Americans, like [INSERT YOUR WORDS – me, my son...], already living with this disease, but could also shed new light into more effective treatments for Alzheimer’s, Parkinson’s, and traumatic brain injuries. Over the long run, more effective treatments will not only improve the lives of the one million Americans living with hydrocephalus, but will also save taxpayer dollars and reduce the burden of unnecessary high cost procedures on the healthcare system.

Sincerely,

[INSERT YOUR SIGNATURE]